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ABSTRACT

The 1997 Amendments to the Individuals with Disabilities Education Act (IDEA) place an emphasis upon improved results for students with disabilities. A coordinated services system is encouraged in order to improve the effectiveness and efficiency of service delivery and accountability for results. To coordinate services with other agencies, state special education administrators must align the implementation of IDEA and state special education laws with other applicable federal and state laws. Intended to assist state education administrators as they work with welfare, health, and other human services counterparts in developing coordinated programs for persons with disabilities, this document discusses key provisions of the Personal Responsibility and Work Opportunity Reconciliation Act of 1996 (PRWORA) and the Balanced Budget Act of 1997 (BBA). The Temporary Assistance for Needy Families (TANF)block grant program, the Supplemental Security Income (SSI) program, child nutrition programs, and Medicaid provisions are discussed. It further describes various state implementation strategies that are benefiting persons with disabilities and discusses selected implementation issues and challenges, including access to quality child care, continued access to SSI, implementation of the Children's Health Insurance Program, use of bundled Medicaid rates, managed care benefits and challenges, and continued access to health insurance. (Contains 47 references.) (Author/CR)

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WELFARE REFORM: ISSUES, PROGRESS, AND IMPLICATIONS FOR PERSONS WITH DISABILITIES

by

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U.S. Office of Special Education Programs

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ABSTRACT

The 1997 Amendments to the *Individuals with Disabilities Education Act* (IDEA) place an emphasis upon improved results for students with disabilities. A coordinated services system is encouraged in order to improve the effectiveness and efficiency of service delivery and accountability for results. To coordinate services with other agencies, state special education administrators must align the implementation of IDEA and state special education laws with other applicable federal and state laws. This document discusses the key provisions of the *Personal Responsibility and Work Opportunity Reconciliation Act of 1996* (PRWORA) and the *Balanced Budget Act of 1997 (BBA)*. It further describes various state implementation strategies that are benefitting persons with disabilities and discusses selected implementation issues and challenges. This document is intended to assist state education administrators as they work with their welfare, health, and other human services counterparts in developing coordinated programs and services for persons with disabilities.

WELFARE REFORM: ISSUES, PROGRESS, AND IMPLICATIONS FOR PERSONS WITH DISABILITIES

INTRODUCTION

Purpose and Organization of Document

The purpose of this document is to discuss welfare reform and its real and/or perceived impacts on persons with disabilities. A brief overview of the *Personal Responsibility and Work Opportunity Reconciliation Act of 1996* (PRWORA) is provided. In addition, one other piece of federal legislation supporting welfare reform will be discussed--the *Balanced Budget Act of 1997* (BBA). The BBA modified the provisions of PRWORA by expanding health care coverage for low-income children through a new entitlement program, the *Children's Health Insurance Program* (CHIP).

Following a brief description of these two federal laws, selected state implementation strategies will be highlighted. This will be followed by a review of several welfare reform impact studies and a discussion of several perceived and/or real impacts of welfare reform upon persons with disabilities, as well as several issues and implementation challenges. The relationship between poverty and disability is strong; therefore, this information is important for state and local directors/administrators of special education to assist them in working effectively with their other agency partners in the ongoing implementation of welfare reform legislation. This interagency work will involve implementing creative welfare reform strategies, implementing solutions to challenges, and measuring impacts so that successful employment of persons with disabilities, as well as those who have children with disabilities, can be achieved.

Information Sources

As part of Project FORUM's work on its cooperative agreement with the U.S. Department of Education's Office of Special Education Programs (OSEP), information from states related to welfare reform and its impact on persons with disabilities or caretakers of children with disabilities was reviewed. In addition, telephone interviews were held with approximately 20 individuals to identify state welfare reform practices as well as various implementation issues impacting persons with disabilities or families/caretakers who have disabilities. Interviewees and reviewers included state directors of special education, other state education and human service agency personnel, federal human service administrators, contractors such as the University of Kansas National Technical Assistance Center on Welfare Reform and Disability, and other experts such as staff from the Bazelon Center on Mental Health Law and the Georgetown University Child Development Center.

In addition, an Internet search was made for pertinent welfare reform articles and information. Internet sources included www.welfareinfo.org, http://managedcare.hhsgovt/program; descriptions/Medicaid/children.htm; and http://www.welfare-policy.org/impact.htm.

WELFARE REFORM PROVISIONS

The Personal Responsibility and Work Opportunity Reconciliation Act of 1996 (PRWORA)

The PRWORA, signed into law on August 22, 1996 by President Clinton, dramatically changed the nation's welfare system into one that requires work in exchange for time-limited assistance. This represented a fundamental shift in the relationship between the federal government, the states, and persons living in poverty. In this section, brief summaries are provided for selected key provisions of PRWORA.

Temporary Assistance for Needy Families (TANF) – Title I

The TANF block grant program replaced the former Aid to Families with Dependent Children (AFDC) and the Job Opportunities and Basic Skills Training (JOBS) program. The TANF program was designed to:

- Provide financial assistance to needy families so that children can be cared for in their own homes
- Reduce dependency by promoting job preparation, work, and marriage
- Prevent out-of-wedlock pregnancies
- Encourage the formation and maintenance of two-parent families (Greenberg & Savner, 1996)

With few exceptions, TANF recipients are required to work after two years of assistance. To count toward state work requirements, PRWORA requires recipients to participate in unsubsidized or subsidized employment, on-the-job training, work experience, community services, twelve months of vocational training, or provide child care services for persons who are participating in community service.

As explained by Golden and DePerle (1998), the PRWORA provided a five-year lifetime limit on receipt of cash assistance. States can reduce this time and refuse to provide cash assistance if recipients are not involved in work activities after two years. However, states are allowed to exempt up to 20 percent of their caseloads from this five-year time limit, and can introduce waivers and create their own cash assistance programs. TANF also emphasizes child support enforcement as a way to increase self-sufficiency, and no school-age minor may receive assistance unless that minor attends school or training.

States with pre-existing waivers under the old AFDC were given added flexibility to maintain these policies instead of the federal five-year TANF limits, but they had to act before October 1, 1999 to claim this flexibility. States were not allowed to renew their waivers, and there are no new waivers allowed under PRWORA. However, even without a waiver, states have had the flexibility to set their own time limit policies because federal time limits do not apply to assistance provided with funds that states must spend to meet state maintenance of effort (MOE) requirements of the

federal law. States can, thus, continue their waiver approaches to time limits by providing assistance to families with MOE funds.

Supplemental Security Income (SSI) for Children –Title II

The SSI program provides cash benefits to financially needy individuals who are aged, blind, or disabled. SSI has paid benefits to children with disabilities since the program's inception in 1974. Until 1996, the Social Security Act did not contain a separate definition of disability for children. A child was considered disabled if he or she had a medically-determinable impairment (or a combination of impairments) that was of comparable severity to an impairment that would disable an adult.

Beginning in 1991, following the 1990 Supreme Court decision in the case of Sullivan v. Zebley, the Social Security Administration (SSA) introduced a new policy of *functional equivalence* to its medical listings and an *individualized functional assessment* (IFA) for evaluating a disability in a child (SSA, 1998).

The PRWORA changed the SSI eligibility rules for children with disabilities in three ways. First, a new and more restrictive definition of childhood disability was established that limited SSI eligibility to children who meet a set of official conditions called the *Medical Listings of Impairments.* An example of changes made to the *Medical Listings* is that *Childhood Mental Disorders* was modified to remove references to maladaptive behavior from the personal/behavior domain or area. The comparable severity criteria were also replaced with a definition of disability unique to children: a "medically determinable physical or mental impairment, which results in marked and severe functional limitations" (SSA, 1997b). Further concerns regarding the changed SSI eligibility rules will be discussed later in this paper.

The evaluation process for children was revised to reflect this new definition, with an emphasis on assessing the severity of impairment. By removing the IFA, a three-step evaluation process was created that might include the functional equivalence of an impairment to a condition noted in the *Medical Listings.* Functional equivalency requires at least two marked limitations or extreme limitation in one area of functioning for a child to qualify under the new SSI eligibility standards.

Section 416.926a of the Federal Regulations for SSI, provides four criteria for determining functional equivalence. Specifically, an impairment may be functionally equivalent to a listed impairment:

- If there are extreme limitations in one specific function (e.g., walking or talking) or limitations in two or more functions;
- If it causes functional limitations in broad areas of development or functioning (e.g., in motor or social functioning) that are equivalent in severity to disabled functioning limitations in listing 112.12 or 112.02;

- If it is chronic and characterized by frequent episodes of illness or attacks or by exacerbations and remissions (e.g., compared to any listing for a chronic impairment or similar episodic criteria); or

- If it requires treatment over a long period of time (at least a year) and the treatment itself (e.g., multiple surgeries) causes marked and severe limitations, or if the combined effects of limitations caused by ongoing treatment and limitations caused by the impairment(s) result in a marked and severe functional limitation.

A second provision within PRWORA tightened the eligibility rules for children with disabilities in that a reassessment of disability status is required at the time they become adults (age 18). The Balanced Budget Act of 1997 (BBA) subsequently modified this provision, allowing an age 18 redetermination to be conducted within one year following the child's 18th birthday, or whenever the Social Security Administration determines that a case is subject to redetermination. Finally, a continuing review of the disability status for all childhood recipients is required every three years for all children under age 19 whose impairments are considered likely to improve.

Benefits to Immigrants – Title IV

Within the PRWORA, a qualified alien is a person who is lawfully admitted for permanent residence. Under PRWORA, states were not required to end Medicaid coverage or eligibility for any qualified aliens residing in the country before August 22, 1996 (i.e., the passage of PRWORA). For immigrants who were qualified aliens receiving Medicaid benefits on August 22, 1996, states were required to continue Medicaid coverage until at least January 1, 1997, after which amendments to State Medicaid Plans could discontinue coverage of these individuals. For immigrants who were qualified aliens residing in the country before August 22, 1996, but who were not enrolled on that date, whether eligible or not, states had the option not to provide Medicaid beginning on August 22, 1996 with an amended State Plan. The PRWORA contained a mandatory ban on Medicaid eligibility for immigrants who were qualified aliens newly admitted to the United States on or after August 22, 1996. This ban was in effect for the first five years they are in the country in that status, after which an immigrant's access to Medicaid is at state option.

Child Care – Title VI

The increase in the proportion of TANF families who are working and the increase in the numbers of hours they must work, makes child care available to families critical for allowing TANF parents to retain jobs. The website of the Office of the Assistant Secretary for Planning and Evaluation (ASPE, 1998b) in the U.S. Department of Health and Human Services, provided a comparison of prior law and the child care changes within the PRWORA. With the passage of PRWORA, child care funding sources were consolidated into the Child Care and Development Block Grant (CCDBG). The CCDBG provides states with child care subsidies to low-income working families to improve affordability, quality, availability, and accessibility of child care services. The PWRORA extended previous requirements that all states establish health and safety standards for the prevention and control of infectious diseases including immunizations, building

and physical premises safety, and minimum health and safety training. Health and safety protections have been extended to all federally-funded child care programs. Child care changes within the PRWORA require that states use not less than four percent of the total child care federal funds received (mandatory and discretionary) to provide consumer education to parents and the public to increase parental choice and improve the quality and availability of child care (such as resource and referral services).

The PRWORA child care changes eliminated guarantees of child care for families on welfare in order to participate in work or training, and for former welfare families that previously received one year of transitional child care help if they left welfare due to earnings. PRWORA also eliminated the special category of at risk child care for families that are at risk of welfare receipt without child care assistance. Requirements that states dedicate funds to early childhood development or to before- and after-school care programs have also been eliminated.

The PRWORA provisions prohibit states from reducing or ending cash assistance to parents of children under age six who have a demonstrated inability to find child care. This is important to parents of children with disabilities in that there are often additional difficulties in finding quality child care, particularly for children with more complex difficulties (e.g., lack of trained personnel).

Child Nutrition Programs – Title VII

To provide support under the National School Lunch Act, Title VII provides grants to each state based on 50 cents for each child enrolled in schools or institutions within the state. The PRWORA clarified that eligibility for free public education benefits under state or local law does not impact benefits for school meal benefits under the National School Lunch Act and the Child Nutrition Act of 1966, regardless of citizenry or immigrant status. Summer Food Services were reduced, and the School Breakfast start-up and expansion grants were eliminated. Funding for the Nutrition Education and Training (NET) Program was also made discretionary.

Food Stamps – Title VIII

The Food Stamps program retains its previous structure as an uncapped, individual entitlement, but restricts eligibility. For example, able-bodied persons age 18-50 with no dependents become ineligible for food stamps unless they meet a new work requirement.

Medicaid – Title XIX

The Medicaid program (Title XIX of the Social Security Act) is the largest source of funding for medical and health-related services for poor people (Waid, 1998). It is a federal-state matching entitlement that pays for medical assistance for eligible needy individuals and families with low incomes and resources. Medicaid provides all eligible children with critical preventative, acute, and restorative health services. Within broad national guidelines established by federal statutes, regulations, and policies, each state does the following:

- Establishes its own eligibility standards
- Determines the amount, type, duration, and scope of services
- Sets the rate of payment for services
- Administers its own program

However, to be eligible for federal funds, states are required to provide Medicaid coverage for certain individuals who receive federally assisted income-maintenance payments, as well as for related groups not receiving cash payments. Medicaid has mandatory *categorically eligible* groups for which federal matching funds are provided. Some examples of *categorically mandatory* eligibility groups are (see: http://www.hcfa.gov/medicaid/meligib.htm):

- Low income families who meet eligibility requirements in the State's AFDC plan in effect on July 16, 1999
- Supplemental Security Income (SSI) recipients who were in place in the State's approved Medicaid plan as of January 1, 1972
- Infants born to Medicaid-eligible pregnant women
- Children under 5 and pregnant women whose family income is at or below 133 percent of the Federal poverty level
- Recipients of adoption assistance and foster care under Title IV-E of the Social Security Act
- Certain Medicare beneficiaries
- Specially protected group who may keep Medicaid for a period of time such as persons who lose SSI payments due to earnings from work or increased Social Security benefits; and families who are protected 6-12 months of Medicaid coverage following the loss of eligibility under Section 1931 due to earnings, or 4 months of Medicaid coverage following the loss of eligibility under Section 1931 due to an increase in child or spousal support

States also have the option of providing Medicaid coverage for other *categorically needy* groups. These optional groups have characteristics similar to the mandatory groups, but the eligibility criteria are somewhat more liberally defined. Examples of the optional groups that States may cover as *categorically needy* groups (and for which they may receive Federal matching funds) are (see: http://www.hcfa.gov/medicaid/meligib.htm):

- Infants up to age one and pregnant women not covered under the mandatory rules whose family income is below 185 percent of the Federal poverty level (the percentage to be set by each State)

- Optional targeted low-income children
- Certain aged, blind, or disabled adults who have incomes above those requiring mandatory coverage, but below the Federal poverty level
- Children under age 21 who meet income and resources requirements for AFDC, but who otherwise are not eligible for AFDC
- Institutionalized individuals with income and resources below specified limits
- Persons who would be eligible if institutionalized but are receiving care under home and community-based services waivers
- Recipients of state supplementary payments
- TB-infected persons who would be financially eligible for Medicaid at the SSI level (only for TB-related ambulatory services and TB drugs)

In addition to the *mandatory* and *categorically needy* Medicaid eligibility groups, states have the option to extend Medicaid eligibility and federal matching funds to a third group of eligible *medically needy* persons who may have too much income to qualify under the mandatory or optional categorically needy groups. States that elect to include the *medically needy* group under their Medicaid plans are required to include certain children under age 18 and pregnant women who, except for income and resources, would be eligible as categorically needed. They may choose to provide coverage to other *medically needy* persons: aged, blind, and/or disabled persons; certain relatives of children deprived of parental support and care; and certain other financially eligible children up to age 21 (See http://www.hcfa.gov/medicaid/meligib.htm). Waid (1998) reported that in 1996, at least forty states had elected to provide certain additional Medicaid services within the *medically needy* eligibility group.

Under PRWORA, persons receiving TANF are no longer automatically entitled to Medicaid. However, if new applicants would have been entitled to Medicaid under the state's previous AFDC rules (i.e., as they appeared in the state plan as of July 16, 1996), they must be reviewed under those *frozen* AFDC rules (Waid, 1998). In effect, the new law created a fourth Medicaid eligibility category (in addition to the *categorically mandatory*, *categorically needy*, and *medically needy* eligibility groups described above).

Although comprehensive Medicaid reform was not included in the welfare reform bill, PRWORA made a change in the eligibility rules governing the Medicaid program. Under the previous law, anyone receiving cash assistance under Title IV-A, the Aid to Families of Dependent Children (AFDC) program, was automatically entitled to Medicaid benefits. Now, TANF, the program that replaced AFDC, limits a family's lifetime cash welfare benefits to a maximum of five years, and permits the state to impose a wide range of restrictions related to employment. In a letter to State Medicaid Directors and TANF Administrators, Olivia Golden, Assistant Secretary for Children and Families and Nancy-Ann Min DeParle, Administrator, Health Care Financing Administration (June, 1998), indicated that in decoupling Medicaid from cash assistance, a new Medicaid low-income family eligibility group was established under Section 1931 of the Social Security Act. The basis for Medicaid eligibility under this group are the income and resource standards and the dependency and specified relative requirements of the AFDC State plan in effect on July 16, 1996. Medicaid eligibility is not tied to the State's TANF eligibility criteria. However,

the law provided states with flexibility to use more liberal income and resource requirements of the TANF program to determine eligibility and also to continue certain AFDC waivers in effect prior to July 16, 1996 that can effectively coordinate Medicaid and TANF eligibility. Golden and DeParle further encouraged states to provide automatic Medicaid eligibility to TANF cash assistance recipients.

In providing assistance to poor families making the transition from welfare to work, states have at least two mechanisms for continuing Medicaid coverage for some or all family members. First, under the authority in Section 1925 of the Act, states must provide up to one year of extended Medicaid benefits (transitional medicaid) to families who, because of increased earnings from work, are no longer eligible for Medicaid under the Section 1931 group. Second, under the authority in Section 1931 of the Act, states can modify the income and methodologies they use to determine eligibility (e.g., modifying the treatment of earned income) to assist families in maintaining Medicaid coverage as the adults transition from welfare to work.

Assistant Secretary Golden and Administrator Dapperly further indicated that the states cannot deny a family Medicaid eligibility simply because the family is ineligible for TANF. States are specifically prohibited from denying or terminating Medicaid eligibility unless all possible avenues to medicaid eligibility have been explored and exhausted. Families who lose Medicaid eligibility under Section 1931 because of increasing earnings are eligible to receive up to an additional year of Medicaid (i.e., transitional Medicaid). They further encouraged states to use TANF funds to provide welfare diversion assistance to families in need, or to require certain activities before a TANF application is taken. In carrying out a diversion program, an aggressive outreach is needed to provide Medicaid information to families and to take all possible steps to assure that eligible children are enrolled in Medicaid and CHIPS.

Social Services Block Grant – Title XX

The purpose of the Social Services Block Grant program (Title XX) is to provide assistance to states to enable them to furnish services directed to:

- Achieve or maintain economic self-support and prevent, reduce, or eliminate dependency
- Achieve or maintain self-sufficiency including reduction or prevention of dependency
- Prevent or remedy neglect, abuse, or exploitation of children and adults unable to protect their own interests
- Prevent or reduce inappropriate institutional care, home care, or other forms of less intensive care preserving, rehabilitating or reuniting families
- Successfully refer or admit for institutional care when other forms of care are not appropriate

The PRWORA allows funding from the Social Services Block Grant (SSBG) to be used to create vouchers for families ineligible for or denied cash assistance under TANF because of a family cap or five-year time limit on benefits.

The Balanced Budget Act of 1997 (BBA)

The provisions of PRWORA were modified by the *Balanced Budget Act of 1997* (BBA). The BBA imposed new restrictions on TANF clients who can participate in vocational education, and created a new welfare-to-work grant program for long-term AFDC/TANF clients. With regard to Medicaid, the BBA allows states to implement managed care programs without going through a waiver process. Programs serving children with special health care needs, however, must still obtain a waiver.

The BBA modified the provision of the PRWORA limiting SSI eligibility for children with certain disabilities, and reinstated Medicaid coverage for those children who were receiving SSI payments on August 22, 1996 (the day the welfare reform bill went into effect) and who, except for the passage of the bill, would have continued to receive Medicaid benefits.

The BBA also created the new *Children's Health Insurance Program* (CHIP) under Title XXI of the Social Security Act. Provisions of the CHIP allow states to expand coverage for uninsured, low-income children under age 19 through a separate child health insurance program, the Medicaid program, or a combination of these programs. Services covered under CHIP must include (at a minimum) inpatient and outpatient hospital services, physicians' surgical and medical services, laboratory and x-ray services, as well as well-baby and well-child care, including immunizations.

Targeted low-income children may enroll in the CHIP program, with *low income* defined as the greater of 200 percent of the poverty line or 50 percent above the Medicaid-qualifying income level. States may not impose different eligibility standards based on diagnosis, or deny eligibility based on a pre-existing medical condition. States that elect to enroll children in a non-Medicaid program have additional options in using countable income, rather than gross or net income that may bring higher income children into the CHIP program.

In addition, states may use the maximum income standards for children with disabilities but not for others, or they may apply more liberal income approaches for this group of children. Fox, Graham, and McManus (1998) reported that states have not set their income eligibility thresholds for children with disabilities higher than those for other CHIP-eligible children. In 1998, they reported that only one state (Colorado) has adopted an income eligibility methodology that would provide greater access for children with disabilities or special needs. Further, only two states (Connecticut and Oregon) have addressed circumstances unique to families with special needs children by providing exemptions to the required period of uninsurance.

In a letter to State Medicaid Directors from Sally Richardson, Director for Medicaid and State Operations, U.S. Department of Health and Human Services (October 1997), the various BBA provisions for children were discussed. Specifically, according to Richardson, the BBA added three

options for states to expand child coverage under Medicaid. First, Section 4912 of PRWORA amended Title XIX of the Social Security Act to give states the option of providing presumptive child Medicaid eligibility for a limited period of time. *Second, presumptive eligibility provided* the opportunity to grant immediate eligibility without first requiring a full Medicaid eligibility determination. Third, Section 4731 amended Title XIX to provide states the option of one year of continuous Medicaid child eligibility. This provision also gave states the option to accelerate the phase-in Medicaid coverage for children under age 19 who live in families with incomes up to 100 percent of the federal poverty level.

STATE IMPLEMENTATION STRATEGIES UNDER TANF

Policies Regarding TANF Work Requirements for Recipients With Disabilities

As stated earlier, the PRWORA allows states to exempt 20 percent of welfare recipients from the five-year work limit in order to assist families who will face extreme difficulties finding and keeping jobs, including persons with disabilities. The strict work requirements and lifetime limits to benefits (i.e., two-year work limit and five-year lifetime limit on receipt of cash assistance) imposed by the PRWORA are forcing states to look at portions of their caseloads that have, in the past, been exempted from work.

Under previous welfare-to-work programs, many recipients with disabilities were exempted from, or had not succeeded in, welfare-to-work activities. For example, persons with learning disabilities were often referred to nonwork-related adult basic education (ABE) programs, rather than occupational training programs. Under TANF, states may use their funds to provide supports beyond income supports for persons, including those with learning disabilities. These supports include education, training, wage supplements, and other services.

Urban Institute researchers (Thompson, Holcomb, Loprest, & Breneen, 1998) reported that during 1998, 18 states had chosen to generally exempt individuals with disabilities from participating in required work activities while receiving cash benefits. Seventeen additional states had implemented a *broadened participation* policy where the work activity requirement for recipients with disabilities is determined in one or more of the following ways:

- Allowing few formal exemptions, but maintaining mechanisms to exempt some recipients with disabilities
- Allowing the case manager to carefully review medical document and determine whether the individual is able to participate in required work activities
- Allowing the case manager familiar with required activities and supports (rather than medical eligibility staff) to determine if the recipient should be exempt
- Having a medical review team review medical documentation and apply more consistent standards for determining exempt status

Finally, at least 23 states have implemented a universal participation policy and no longer exempt any recipients from participating in work activities. Thompson et al. (1998) noted that states with universal participation policies have adopted broader definitions of work activities to include activities that promote self-sufficiency such as education, training, and wage supplements.

In general, rather than exempting these hard-to-serve recipients from work participation and other TANF requirements, states are implementing a variety of strategies to assist welfare recipients with special problems such as physical and learning disabilities, substance abuse, mental health problems, poor communication skills, little work experience, attitudinal problems, history of welfare dependence, and multiple children. Selected state strategies are discussed below.

Family Literacy Programs

Ganzglass (1998) reported that people with strong basic education and literacy skills work and earn more than individuals with low skill levels. Further, family literacy programs that achieve results over more than one generation of a family help strengthen families and make adults more competitive in the job market. With welfare reform's shift from extensive pre-employment training to work first, states are using family literacy to complement the education of working individuals with low literacy levels. Family literacy can also help children become better prepared for school (Ganzglass, 1998).

Ganzglass (1998) described several state efforts to link family literacy programs with welfare reform efforts:

- Under a state welfare law, Ohio allows a county to contract with a school to enable a work program participant with an enrolled child to volunteer or work for compensation at the child's school.

- In Canton, Ohio, a family literacy program combines ten hours of work-focused basic skills training with twenty hours of work experience within the school.

- In Louisville, Kentucky, the Jefferson County Public School System Family Education Program designed the *Apprentice Transition: From Welfare to Work* family literacy program that offers TANF recipients increased levels of job shadowing and work experience in school district jobs as teachers' aides, bus monitors, maintenance workers, office assistants, or food service workers.

- In Rochester, New York, welfare recipients can attend a family literacy program in the morning and a vocational education class in the afternoon. The family literacy coordinator acts as the student's case manager in coordination with the department of social services' case manager to provide follow-up services after job placement.

- In Eau Claire, Wisconsin, a family literacy program (e.g., preschool component) is designated as an allowable site to be supported with child care funds.

- Tennessee has an individualized literacy program for welfare recipients with learning disabilities with hopes of increasing the level of parental involvement in the child's school.

Accommodations for Training and Employment

As the two-year limits for recipients to obtain employment approaches, there is increasing concern that there is insufficient time for hard-to-serve welfare recipients, including those with disabilities, to participate in the state's job training programs, and find work. Providing adequate work supports and incentives for persons with disabilities as they transition from welfare to work will be a continuing challenge. State and county welfare agencies can consider offering on-site vocational counseling with professionals trained to administer disability assessments and vocational evaluations, while tailoring existing services to clients' needs. To support state efforts, in March 1998, President Clinton signed an Executive Order that called on programs that work with welfare clients to incorporate reasonable accommodations into education, job training, and employment settings.

In discussing this problem, Johnson and Meckstroth (1998) provided several observations:

- People with any level of disability are much less likely to be employed than those without a disability, and they have a greatly reduced earnings capacity (McNeil, 1997).

- People with work disabilities are more than twice as likely (16 percent versus 7 percent) as other workers to be unemployed, but actively seeking work (Mashaw & Reno, 1996).

- A large number of adults with learning disabilities are thought to drop out of job training efforts because the programs are not designed to meet their learning needs (Gerber & Reiff, 1994).

Accurate identification of clients with disabilities and their specific needs are critical in working with recipients with disabilities. TANF caseworkers can be used to screen and refer clients with learning disabilities to vocational rehabilitation programs for further testing and determination of severity. Some states are improving or developing screening and assessment procedures. For example, Johnson and Meckstroth (1998) reported that Washington and Kansas are implementing pilot intake models that identify learning disabilities for use by case workers. Wisconsin provides training in identifying learning disabilities for welfare case managers and caseworkers. Illinois and Rhode Island are also beginning pilot projects in this area.

Wisconsin's Council on Developmental Disabilities has funded a toll-free telephone hotline, the *Wisconsin Works (W2) Disabilities Hotline*, to provide assistance for clients with disabilities, including those who are or are not receiving SSI support (Johnson and Meckstroth, 1998). To support this hotline, the W2 program offers advanced training to case managers in identifying,

working with, and making appropriate referrals for clients with learning, physical, and cognitive disabilities. Training is supplemented by the *W2 Case Management Guide* that provides case managers with information on identifying and serving clients with disabilities.

States are helping welfare programs develop links to community-based organizations with expertise in disability issues. Efforts are also being made to assist employers in finding ways to re-configure job structures, working hours, and work sites, as well as to ensure health coverage and continued assistance on the job for persons with disabilities. In Florida and New Jersey, TANF funds are being used to support job placement and retention for welfare recipients with learning and other disabilities.

Brown (1998) described other state efforts to support persons with disabilities who are recipients or children of adult recipients:

- The New Hampshire Department of Health and Human Services contracts with the Department of Education to employ a disability support specialist.
- Kansas is recruiting community colleges to offer intervention courses to help recipients with learning disabilities build skills in areas such as setting work priorities.
- Wisconsin encourages local welfare agencies to build partnerships with local literacy councils that specialize in providing one-to-one tutoring.

Use of Adult Education, Vocational Education, and Vocational Rehabilitation as Welfare Reform Strategies

Adult education, vocational education, and vocational rehabilitation are critical welfare reform strategies to help recipients acquire needed job skills. Research suggests that positive employment and welfare outcomes can result when persons with disabilities receive appropriate vocational rehabilitation services (U.S. General Accounting Office, 1996; and Dean and Dolan, 1991). For example, people with learning disabilities can be productively employed if remedial education and occupational training are successful, and if they are helped to compensate for their disability in the workplace. Several state welfare departments are collaborating with vocational rehabilitation departments to provide diagnostic testing and support services for welfare recipients with disabilities.

Some states have implemented innovative collaboration between welfare agencies and the vocational rehabilitation and vocational education agencies. For example, Kentucky has funded the adult education agency to provide training in job and life skills that would count toward the work requirements. Kentucky also has developed cooperative agreements between the TANF and vocational rehabilitation agencies. A strong referral link exists between the welfare agency and vocational rehabilitation agency in Alabama. Welfare workers refer clients to vocational

rehabilitation for assessments and identification of disabilities, identify needed accommodations and services necessary to prepare clients for work, and transition these clients to work.

Development of Coordinated Service Systems

Welfare agencies can facilitate the successful transition of clients with disabilities from welfare to work through interagency partnerships and the provision of coordinated and integrated remediation, rehabilitation, and employment-related services. Some states are improving services for school age and adult persons with disabilities by maximizing the flexibility provided by TANF and CCDBG to coordinate funding sources and services at the local level. Funds from the TANF block grant, CCDBG, and other resources are being combined.

State welfare departments are collaborating with education departments to address the learning and career development needs of welfare recipients while they are still in school. For example, TANF agencies can cooperatively work with schools to develop a child's Individualized Education Plan (IEP) or a coordinated services plan that involves several agencies.

The National Governors' Association (NGA) Center for Best Practices (1999) reported on several initiatives carried out within the states to better coordinate services for children across agencies and programs. For example, Missouri, Oklahoma, and Wisconsin are promoting cross-system collaboration at the local level. Alabama, Colorado, Florida, Michigan, Texas, and Wisconsin have been developing seamless child care systems (i.e., coordinated and integrated interagency programs and services). The *Washington Families and Work Initiative* successfully provides family support services to coordinate child care, parent services, and family support services with employment and training services that welfare recipients need to secure and maintain employment. California, Massachusetts, Kentucky, New Jersey, and Washington have moved to consolidate child care assistance within one agency or system.

Other state coordination efforts reported by the NGA Center for Best Practices (1999) include:

- Maryland has 27 Family Support Centers that work with local departments of social services to support welfare recipients as they seek employment.
- Missouri has pooled funds from five state agencies to empower its 86 local Caring Communities to better integrate their human services and economic resources.
- Wisconsin has funded a Children's Services Network that provides central access to information on housing, child care, child welfare, charitable food and clothing centers, and other related support services.
- Colorado and Indiana have successfully leveraged both financial resources and technical expertise from the private sector to support interagency efforts.

- Delaware is coordinating efforts across multiple agencies that oversee child care.

Child Care

In the spring of 1998, the NGA Center for Best Practices asked states to share their efforts to provide high quality child care for families receiving TANF, families moving from welfare to work, and working families. They found that several states are establishing quality child care standards. In Georgia, the *Standards of Care Initiative* awards a Center of Distinction certificate to each child care center adopting state voluntary standards of care. The *Kansas Standards for Early Childhood Education* provide a consistent measurement tool to evaluate all early childhood programs. States are also streamlining their licensing operations and improving their oversight of state licensing requirements (NGA, 1998).

All states are subsidizing child care at some level, and as of 1998, 21 states were increasing the amount spent on training child care providers (Tufts University Center on Hunger and Poverty, 1998, cited in Woolverton, Wischmann, & McCarthy, 1998). States such as Delaware, New Jersey, and Tennessee are improving the quality of training for child care providers by increasing access to training opportunities and creating professional development systems that include a career ladder for early childhood professionals. The Mississippi Office of Children and Youth utilizes a mobile unit to bring training to child care centers. Live video conferences that feature state and national experts and co-trainers are used in New York.

Whitney, Groginsky, and Poppe (1999) reported on initiatives that are leveraging TANF and other State and Federal resources. Examples of these initiatives are in North Carolina, Nevada, and Illinois involving inclusive child care for young children with and without disabilities.

- North Carolina has utilized the following sources to fund inclusive child care: Parts B and C of the Individuals With Disabilities Education Act (IDEA), the Maternal and Child Health Block Grant Funds, Early Head Start, Head Start, CHIP, and Medicaid. Program activities have included recruiting and training inclusive child care providers, providing assistive technology and specialized therapy, and using a state funded early intervention service program. Legislation passed in 1998 coordinated the new CHIP with Medicaid by including the same package of services for children with special needs as included in Medicaid (e.g., dental coverage; hearing, vision, and speech screening; and medical equipment for children in child care).

- State administrators in Nevada developed a strategic child care plan to improve the quality of child care for children with special needs. The Material and Child Health Block Funds are combined with Part C of IDEA, Head Start, and state funds. These funds are used to support inclusive child care professionals in both urban and rural settings. Interagency and community-based teams provide training and support for special needs children in inclusive community settings. Nevada's Early Childhood Services Program provides mental health and family support from several agencies. The Early Intervention Partners program, in collaboration with the University of

Nevada, provides early intervention training to family and center-based child care providers focusing on inclusive programming for young children with special needs.

- A five-year University of Illinois based project, Project PIECE, is preparing Illinois teachers to meet the diverse needs of children with disabilities within integrated preschool settings.

Implementation of the CHIP to Expand Health Insurance Coverage

State CHIP efforts can address the care requirements of children with disabilities and other special needs in a variety of ways. First, states have the option to make children with disabilities eligible for CHIP at higher income levels than other children in order to assure access to a broad scope of specialty services with reasonable cost-sharing, and to establish contract provisions for an appropriate and effective system to delivery services for children with chronic conditions.

Fox, Graham, and McManus (1998) reported that for the most part, states have not structured their CHIP program with particular attention to children with special needs. However, a number of states have implemented innovative strategies. They reported that Florida has the most comprehensive non-Medicaid CHIP program. This program will enroll children with chronic physical, developmental, or serious behavioral conditions in a special capitated managed care plan with Medicaid benefits delivered by an approved network of pediatric primary and specialty care providers. Children in Florida with chronic or potentially chronic physical or developmental conditions and a capped number of children with serious emotional disturbance or substance dependency receive the same benefit package available to Medicaid beneficiaries. In Connecticut, children with physical or developmental problems or serious mental or substance abuse disorders are eligible for services in addition to those offered through the state's standard non-Medicaid CHIP program, HUSKY Part B. These additional services include ancillary therapy services, medical devices and equipment, home health services, and orthodontia assistance. North Carolina also uses a non-Medicaid program for all CHIP-eligible children in which those with physical or developmental conditions meeting specific criteria have access to expanded coverage equivalent to the full package of benefits available under Medicaid.

In Massachusetts, all children with physical, mental, or developmental conditions that meet the SSA definition of disability are enrolled in the Medicaid program regardless of whether family income would otherwise qualify them for non-Medicaid CHIP coverage. Connecticut is providing the same population of children with extensive wraparound benefits to augment its basic benefit package and is requiring that these services be delivered through an approved network of specialty providers. North Carolina has implemented a wraparound benefit package for children with physical or developmental problems. Massachusetts is enrolling all children who qualify as disabled into the state Medicaid program, but exempting them from managed care.

IMPACT STUDIES

Completed studies *specifically* reviewing the impact of the PRWORA or the BBA upon school age or adult clients with disabilities or parents/caretakers of children with disabilities were limited. However, there are a number of impact studies that have looked at the preliminary effects upon all eligible recipients, including persons with disabilities or parents/caretakers of children with disabilities.

Even though no single definition of disability has been used by the welfare community, there are a significant number of school age and adult recipients who have disabilities. Estimates of adult recipients with learning disabilities have ranged from 25 to 40 percent (Kramer, 1998). New York State (1998) reported on national studies that have indicated almost 90 percent of welfare recipients who are between the ages of 27 and 35 experience one of five barriers to employment (i.e., low basic skills, substance abuse, a health limitation, depression, or have a child with chronic medical condition or serious disability). Studies in Kansas, Ohio, Washington State, and Oregon have shown that as many as 35 percent of welfare recipients have learning disabilities (Brown, 1998).

Meyers, Lukemeyer and Smeeding (1996) reported that nearly one-fifth of current and recent welfare recipients were found to care for children with disabilities or chronic physical or mental illness. Loprest and Acs (1996) found that between 11.6 and 15.9 percent of the families receiving Aid to Families with Dependent Children (AFDC) cared for a child who demonstrated limited age-appropriate activities. In addition, 3.8 percent of families cared for a child with a severe or chronic condition such as an orthopedic condition or epilepsy, and between 13 and 19 percent of recipients had a child with a serious behavioral or medical problem (Reischi, 1998).

For example, in April 1999, the National Conference of State Legislatures reported that all states have implemented welfare reform. Recipients know to expect that cash assistance is temporary and participation in work activity is required. States are providing supports for employment including child care and transportation assistance. Welfare agencies have forged new partnerships with other government programs, community organizations, and businesses. Concerns, however, were noted that reduced welfare caseloads have slowed in some states. In addition, many states offer inadequate assistance to recipients with serious barriers to working, including those with disabilities (see: http://www.welfare-policy.org/impact.htm).

In May, 1999, an Associated Press 50-state survey showed that the number of people on welfare is at a 30-year low nationwide (Associated Press, May 1999). This survey explored reasons for welfare reform success. The strong economy was listed as a critical factor for success. In addition, the 50-state survey showed that although some families have lost their benefits because of time restrictions, liberal time extensions and exemptions within the states have resulted in minimum impact on welfare rolls in 13 of the 22 states that have shorter time periods (less than five years) for employment, and where time deadlines have been reached. In some states, nearly half of the people leaving welfare were dropped for failing to follow rules (e.g., not keeping appointments such as welfare interviews and failing to provide required information).

The Children's Defense Fund and the National Coalition for the Homeless (1998) have released a joint report that shows that more families are moving from welfare to work; however, many of them are faring worse than before. Many former recipients lack food, needed medical care, and stable housing. Some states and communities have creative, innovative and supportive programs for helping families find sufficient above-poverty employment. Findings of the Children's Defense Fund and the National Coalition for the Homeless include:

- Only a small fraction of welfare recipients' new jobs pay above-poverty wages; most of the new jobs pay far below the poverty line.
- Many families who leave welfare are losing income or not finding steady jobs at all.
- Extreme poverty is growing more common for children, especially those in female-heads-of-households and working families.
- Many families leaving welfare are struggling to get food, shelter, or needed medical care; many are suffering even more hardships than before.
- Many families are not getting basic help (such as child care, medical coverage, food, or transportation) that might enable them to sustain work and care for their children on very low wages.
- Many families are being denied cash assistance because of failing to participate in required activities because of lack of transportation, lack of child care, a health condition, or mental health problems.

In February, 1998, representatives from forty-two states attended a conference to share follow-up data and tracking of welfare recipients. This conference was sponsored by the U.S. Department of Health and Human Services, the NGA, the National Conference of State Legislatures, and the American Public Human Services Association. At this conference, data from eleven states (Indiana, Iowa, Kentucky, Maryland, Michigan, Missouri, Montana, New Mexico, South Carolina, Tennessee, and Washington) indicated the following related to implementation of welfare reform (NGA, 1998):

- TANF caseloads have dropped 30 percent since fiscal year 1994.
- Between 50 and 60 percent of recipients that leave welfare find jobs.
- About 40-50 percent of recipients have been sanctioned for not complying with new requirements subsequently find work.
- For most jobs, workers receive pay higher than minimum wage, but not enough to raise a family out of poverty.

- Child care and transportation continue to be difficult barriers for some families.

- Most families previously eligible for AFDC continue to receive some form of public help such as food stamps, child care, and Medicaid.

- About 20 percent of the families that leave welfare come back within several months.

In September, 1998, the U.S. Department of Health and Human Services awarded approximately $2.9 million in grants to study the outcomes of welfare reform on individuals and families who leave the TANF program, as well as those who apply for welfare, but are never enrolled because of non-financial eligibility requirements, and/or who appear to be eligible, but who are not enrolled. These results should be available within a couple of years. With this federal support, 13 state and county grantees are measuring outcomes such as employment and earnings; return to the TANF program; participation in other public programs such as food stamps, Medicaid, child support, and child welfare; and family and child well-being.

States such as Missouri, New Mexico, and Tennessee are using their universities to conduct follow-up studies on welfare recipients. Maryland and North Carolina are using unemployment insurance wage records to track employment-related outcomes. North Carolina is also tracking outcomes for children.

Researchers from the Urban Institute (1998) studied the disability profile of recipients of the previous AFDC program and the extent to which there is a limited ability to work because of the disability of the mother or that of her child. The results questioned whether the 20 percent exemption is high enough to accommodate the numbers of recipients who are hard to place in jobs.

A report was recently released by Families USA (Klein, May 1999) that examined the connection between welfare reform and the loss of health insurance. This study reported that children made up 62 percent of the people who lost health insurance as a result of welfare reform. Most of these children were likely still eligible for Medicaid and should not have lost coverage. This study further highlighted three reasons for loss of coverage:

- People who move from welfare to work often lose their Medicaid either because transitional Medicaid runs out or because they were never offered it in the first place, and are usually in low-wage jobs that do not offer health care.

- Termination from welfare often results in illegal closure of Medicaid cases, despite the fact that most people remain eligible for Medicaid.

- States deter people from applying for welfare and, despite the fact that it is a violation of federal law, make it difficult for some of these people to apply for Medicaid.

There are two projects funded by the Social Security Administration, researching the impact of Welfare Reform legislation on children with disabilities who lost SSI cash benefits because of the revised standard of disability for children. The first project is being carried out by the Rand Corporation and will continue through approximately May 2000. It will provide descriptive and empirical information, including the effects on family income, parental labor force involvement, as well as access to Medicaid and other forms of insurance. The second project studying the impact of welfare reform legislation on children with disabilities impacted by the change in disability standard, is being conducted by Mathmatica. The first phase of the Mathmatica study was to develop a survey design by fall, 1999. The second phase is to implement the survey beginning in mid to late 2000.

SELECTED IMPLEMENTATION ISSUES AND CHALLENGES

Access to Quality, Safe, and Affordable Child Care

Securing high quality day care is a critical task for families making the transition from welfare to work. Child care subsidies are available to those cooperating with their state's welfare to work programs. States such as New York and Oklahoma have reported that finding qualified persons to care for children with disabilities remains a critical barrier to meeting the TANF work requirements. There are many problems finding appropriate, safe, and affordable care. The ability to count the hours a parent cares for a child with a disability toward TANF participation is, however, a positive aspect of the TANF program.

Despite the efforts within the states to improve the quality of child care and recent increases in CCDBG funding, children are waiting for child care all over the country. In her recent Congressional testimony, Helen Black, Director of Child Care and Development for the Children's Defense Fund reported that many children are not eligible for help due to low state eligibility cutoffs (Black, 1999). Many who are eligible, cannot get child care either because they are put on waiting lists or are turned away due to inadequate funds. Low subsidy rates for child care and high child care fees limit parent choice unless the parent is able to pay the difference between what the subsidy rate will cover and the provider's actual rate. Other families are not aware of help that is available. If families are to keep their jobs and stay off welfare, much more needs to be done to provide adequate child care assistance. Black (1999) found that fear of being overwhelmed by requests for child care helps encourage administrators to set up administrative barriers that deter both TANF and low-income working families from taking advantage of child care subsidies. Caseworkers may give families confusing information or incomplete and outdated information about available child care.

Continued Access to SSI

Eligibility Redeterminations

The PRWORA contains provisions guaranteeing continuing Medicaid eligibility to children who lose eligibility for Social Security Income (SSI) under the new disability standards that was enacted in the BBA. Under the PRWORA, a child's medically determinable impairment or

combination of impairments must cause more serious impairment-related limitations than the post Zebley rules required. The PRWORA required the Social Security Administration (SSA) to:

- Notify no later than January 1, 1997, beneficiaries who were eligible for SSI benefits on August 22, 1996, and whose eligibility might be affected by the PRWORA, that their eligibility might be redefined.

- Redetermine the eligibility of such beneficiaries using the same definition of disability for children no later than one year after the date of the law change (i.e., extended to February, 1998 by the Balanced Budget Act of 1997).

- Redetermine eligibility to determine those who are eligible for SSI in the month before they attain age 18. The Balanced Budget Act of 1997 now provides that SSA may perform an age-18 redetermination during the one-year period after the child's 18th birthday in lieu of a continuing disability review, as determined appropriate by SSA. Teachers can play an important role by making sure that the SSI redetermination process is folded into the IEP transition process, particularly in working with SSI, the student, and the family to facilitate redetermination the month before a student becomes 18.

- The SSA periodically reviews the cases of all disability beneficiaries to determine if a medical condition has improved to the extent that they are no longer eligible for benefits.

The RAND Corporation (Rogowski et al., 1998) completed an evaluation of the effect of the 1996 welfare reform legislation on SSI benefits for 263,000 children with disabilities and found that 53 percent had an unfavorable redetermination. The researchers identified a number of concerns about corrective actions taken (e.g., redetermination reviews and proper parent/claimant notifications). First, concerns were raised about the precision of SSA's coding. SSA found that a large number of children with the computer code for mental retardation (MR), did not, in fact, have MR. Since there have not been codes for all possible impairments, a code such as MR was selected that was closely analogous. In addition, some children who were accurately diagnosed with MR in the past lost eligibility because they did not have functional limitations severe enough to meet a disability listing within the *Medical Listing of Impairments*.

In November 1997, state Medicaid directors were required by the SSA to re-open determinations for children who were receiving SSI payments on August 22, 1996, but who lost their eligibility because of the new disability definition. Specifically, they were asked to apply the provisions of Section 4913 of the BBA to determine if these cases were eligible for continued Medicaid assistance.

Implementing Age-18 Redetermination

As discussed above, the PRWORA requires redetermination for youth receiving SSI benefits within one year after reaching age 18. At this age, childhood eligibility criteria are replaced with those for adults, and these criteria place an emphasis on the individual's capacity to earn cash through paid employment. Auxter et al. (1999) reported that as a result, 56 percent of the 63,000 age 18 redetermination have been recommended for cessation nationally. For working-age SSI participants, employment decisions are often influenced by the potential loss of program eligibility (National Council on Disability, 1997).

Transition-age individuals with disabilities have also reported the potential loss of cash assistance and health insurance as barriers to employment (Louis Harris and Associates, 1998). Auxter et al. (1999) reported that the high number of children and youth with disabilities removed from SSI may have increased fears of losing program eligibility among those who remain on the rolls. Therefore, SSI participants under the age of 18 may purposefully restrain work activity to avoid the risk of eligibility loss. Transition-age participants over 18 years of age may not seek paid employment to avoid triggering a medical improvement review. It is important that federal and state policies remove these identified barriers to employment and promote paid employment experiences for transition-age individuals with disabilities.

Definition of Childhood Disability for SSI

As discussed earlier, the PRWORA requires that to qualify for SSI benefits, children must have a physical or mental condition that is characterized by a "marked or severe functional limitation" of substantial duration. The reference to "comparable severity" in the old law was deleted. The law also mandated that the Individualized Functional Assessment (IFA) for children be discontinued. In addition, maladaptive behavior has been eliminated in the domain of personal/behavioral function for determining whether a child is disabled.

The *Medical Listings of Impairments* used by the SSA under PRWORA to establish eligibility was implemented in 1977, and some of the *Medical Listings* are now clinically inappropriate and out-of-date. The American Academy of Pediatrics has recommended that modifications be made to the *Medical Listings* that include criteria enabling children with multiple disabilities to be eligible for, or remain in, the SSI program regardless of diagnosis (Perrin, 1998).

Elimination of the Individualized Functional Assessment (IFA)

As stated earlier, the Individualized Functional Assessment (IFA) was eliminated in determining SSI eligibility. In the past, the IFA supplemented the *Medical Listings* by allowing state disability examiners to individually assess how children's disabilities affected their ability to function in various areas of daily activity. In the past, up to one third of eligible children qualified through the IFA, and among all children who qualified through IFA, 42 percent had a mental disorder, and 32 percent had mental retardation. The largest group affected by elimination of the IFA are children with serious mental, emotional, and behavioral disorders. With this change, some

children don't qualify through the more restrictive and possibly out-of-date *Medical Listings* (Woolverton, Wishmann, & McCarthy, 1998).

On July 7, 1998, the American Academy of Pediatrics appeared before the Subcommittee on Social Security and Family Policy, Senate Finance Committee and recommended that new methods be developed to assess functional abilities in the context of disability, rather than relying on the *Medical Listings* alone (Perrin, 1998). The Academy stressed that a functional component be integrated into the overall assessment of a child.

Implementation of CHIP

In April, 1999, it was estimated that 11 million American children and teenagers had no health insurance. This is of great concern because healthy children learn better and faster than those who are not healthy. As discussed earlier, Title XXI of the Social Security Act (Section 4911 of the BBA of 1997) created a Children's Health Insurance Program (CHIP). In addition to expanding health coverage to a broader group of students, the use of private insurance (as permission is granted by the parents) expands Medicaid services for students with disabilities including speech, occupational, and physical therapy. Without medical insurance, students with and without disabilities may not be able to participate in extra-curricular activities to the fullest extent. In addition, young children without insurance are less likely to benefit from well-baby and well-child care, including immunizations, and case management may be inadequate.

As described earlier, Fox, Graham, and McManus (1998) reported that several states have adopted innovative approaches to augment benefits available under their non-Medicaid plans for children with disabilities. They also reported that most states are focused on enrolling eligible children into their CHIP programs. Fox et al. (1998), however, challenged states to examine a range of alternative strategies to enhance their CHIP program in order to reduce or eliminate unmet needs among children with chronic conditions. For example, in 1998, they reported that states had not set their income eligibility thresholds for children with disabilities higher than those for other CHIP-eligible children. In addition, only one state had adopted an income eligibility methodology that would provide greater access to coverage for children with disabilities or special needs. They also reported that only two of the states with exemptions to their required period of uninsurance had addressed circumstances often faced by families whose children have special needs.

States have a wide range of options for designing their CHIP benefit packages. In analyzing the 23 CHIP benefit packages that had been approved by HCFA, Fox et al. (1998) reported that 11 states offered the full package of Medicaid benefit which covers all medically necessary services for children. However, three states utilized non-Medicaid coverage that did not include case management and care coordination services, impatient substance abuse services, or nursing care services, and that also limited ancillary therapies and outpatient mental health and substance abuse treatment services. All non-Medicaid programs impose limits on most services that are important to children with special needs. For example, coverage of specialized or chronic care services (e.g., ancillary therapies, durable medical equipment and disposable medical supplies, home health care, nursing care, case management and care coordination) are either nonexistent or limited in such plans.

Fox et al. (1998) reported that case management and care coordination services were not covered in three states, and these benefits are available only for children with mental conditions in two states.

The reader is encouraged to examine the full report by Fox et al. (1998) in which they provide other examples of good practices as well as areas for needed innovative or alternative strategies to more fully serve children with disabilities, including those with chronic conditions. In addition to variations in eligibility policies and CHIP benefit packages briefly described above, Fox et al. (1998) also discussed state variations and challenges within plan arrangements (e.g., structuring the insurance arrangements for furnishing services), as well as within cost sharing requirements on families whose children participate in the CHIP program (e.g., premiums, deductibles, copayments, or coinsurance).

Use of Bundled Medicaid Rates

An issue has recently surfaced regarding the use of a *bundled rate* method of payment for medical services provided to Medicaid-eligible children in school. This method permits schools to minimize paperwork by billing for a package of medical services, rather than each individual service provided to each child as has been the Medicaid billing practice in the past.

> A bundled payment rate exists when a state pays a single rate for one or more of a group of different services furnished to an eligible individual during a fixed period of time. The payment is the same regardless of the number of services furnished or the specific costs, or otherwise availability rates of these services. The bundle may include two or more components usually provided by different providers, each with their own unique provider qualifications, even if the components fall within the same 1905(a) service category. For example, a bundling exists when two or more component services are provided under the rehabilitative services benefit even if all of the school-based services are identified in the state plan as being contained within the one 19045(a) service category (Richardson, 1999).

In a letter from Sally Richardson to State Medicaid Directors (May 21, 1999), Health Care Finance Administration (HCFA) federal policy was clarified to no longer recognize bundled school-based health services rates as acceptable for the purpose of claiming federal financial participation. This decision was based on the concern that bundled rates for school-based providers are not related to a specific type of procedure and are generally not available to all qualified providers in the community who might want to be similarly reimbursed. Also, schools do not maintain the types of medical documentation that establish the reasonableness or accuracy of a rate. Section 1902(a)(3) of the Social Security Act requires that states have methods and procedures to assure that payments are consistent with efficiency, economy, and quality of care. It was determined that these conditions are not met with the current bundled rate methodologies within the states.

Managed Care Benefits and Challenges

The traditional fee-for-service system is rapidly being replaced by managed care systems with an emphasis on primary and preventive care. In recent years, many states have begun requiring some Medicaid beneficiaries to enroll in managed care plans. As of June 30, 1997, 48 percent of all beneficiaries were enrolled in managed care plans [Office of the Assistant Secretary for Planning and Evaluation's Disabilities and Managed Care (ASPE), 1998a].

Medicaid and Medicare have historically been reluctant to require persons with disabilities to enroll in managed care programs because these persons often require a significantly different scope of health care services than the typical health maintenance organization enrollee. However, policymakers are more frequently turning to managed care systems to control utilization and expenditures, while maintaining quality care for these high-cost populations. Florida, Texas, and Maryland are examples of states that include special needs children in broader efforts to expand Medicaid managed care (ASPE, 1998a).

Adams (1995) and Shapland (1997) reported the following advantages of managed care:

- There are fewer out-of-pocket expenses for parents.
- Health care needs can be addressed in one location.
- Unnecessary procedures are less likely to be done.
- Providers and services often are in locations convenient for patients.
- Consumer satisfaction is regularly surveyed.
- Patients receive continuity of care if they stay with providers in the network.

Adams (1995) reported that families and providers face real and imagined threats from benefit limiting or capitation models of managed care. Providers may over-diagnose and over label to enable children to receive more services. Or, conversely, to stay within budget, providers may be reluctant to provide the necessary levels of case management, rehabilitation, housing, social services, mobile outreach, crisis intervention, or long-term supports needed by children and youth with disabilities.

Adams (1995) and Shapland (1997) also discussed the following managed care disadvantages and challenges:

- There are limitations on access to specialists and doctor choices, making it more difficult for persons with complex disabilities to see an appropriate caregiver.

- Costs discourage primary providers from referring patients to specialists outside the network that may result in the loss of speech, physical, and occupational therapy, as well as the inability to obtain new medication and treatment.

- Plans may require members to change doctors if their current doctor is not in the plan/network.

- Some managed care plans restrict drug choices to a predetermined formula or list of drugs or only provide certain brands or models of medical equipment.

- There may be caps on mental health services or service coordination for dual diagnoses.

- The eligibility criteria of "medically necessary" disregards training or therapy needed to increase personal capabilities.
- Standards of care and quality assurance may not be adequate--particularly related to more specialized treatment and care.

Specific Medicaid populations, referred to as *carve out* populations, may continue to receive their services in a traditional fee-for-service system after the implementation of managed care in a state. For example, within Rhode Island, children with serious emotional disturbance are a *carve out population* and continue to receive services on a fee-for-service basis. Under a managed care waiver, New York is developing an integrated delivery system where counties are responsible for providing comprehensive community mental health services including school-based services for students with serious emotional disturbance, out patient clinics, home-based services, and respite care.

There are managed care implications for the delivery of early intervention services for children birth to three years with disabilities because many of these young children are Medicaid eligible and require services supported by Medicaid. However, states have voiced concern about the shortage of adequately trained early intervention providers in managed care networks.

In addition, states are concerned that the delivery of high quality early intervention services through managed care may be compromised by providers' lack of knowledge about child development and disability issues, their inadequate information about services and supports through federal programs such as Early Periodic Screening, Diagnosis, and Treatment (EPSDT), Part C of IDEA, and the coordination of these programs.

The way managed care gatekeepers address the needs of families may reflect their lack of experience with young children with special needs. With the goal of controlling costs, needed medical and therapeutic services may be limited. Managed care arrangements involving capitation (i.e., whereby plans or providers are paid a fixed fee per enrollee for delivering a defined set of health services) can attempt to minimize costs by limiting hospitalization, referrals, expensive therapeutic services, such as developmental therapy and family counseling, and other supports such as transportation. Specifically, managed care providers may not have an incentive to deliver a comprehensive package of early intervention services and supports to infant with disabilities and their families with complex needs since the capitation rates for these children and families are no different than the rates for other children without special needs.

Continued Access to Health Insurance

As discussed earlier, the study released in May 1999 by Families USA (Klein, 1999) examined the connection between welfare reform, the loss of Medicaid coverage, and unintended consequences resulting from loss of insurance coverage. According to this report, as a direct result of welfare reform, an estimated 675,000 low-income people have become uninsured, 62 percent of which were children, including those with disabilities under age 19. Most of these children were probably still eligible for Medicaid and should not have lost coverage. Many recipients are losing their Medicaid either because transitional Medicaid has run out or because they were never offered transitional assistance.

Once off Medicaid, many people who find work are offered low-wage jobs that do not offer health insurance, resulting in increased numbers of people who are uninsured. The Families USA study concluded that federal and state governments will need to work together to fix this problem (Klein, 1999). By July 1, 1999, current welfare recipients reached the two-year time limit when they must be working in order to keep their welfare benefits. Three years later, by July 1, 2002, individual families will have reached their lifetime limit. As these limits are reached, it is likely that many persons will lose their Medicaid coverage and become uninsured. The Families USA study concluded that despite the fact that we have a clear national priority to help low-income people with the costly burden of health insurance, thousands of people are falling through the cracks when they leave welfare.

Other Unintended Outcomes and Outstanding Issues

In addition to the concerns already described above, the following unintended outcomes and outstanding issues were identified by various impact studies, interviewees, and/or other persons with expertise in this area who reviewed early drafts of this paper:

- Welfare reform has contributed to reducing the Medicaid enrollment. Klein (1999) reported that 1.25 million people with incomes under 200 percent of the federal poverty threshold lost their Medicaid coverage as a result of welfare reform. Since the enactment of Federal welfare reform legislation in 1996, Medicaid enrollment of children has actually declined by 8-10 percent.

- There are a number of reasons that many people, including those with disabilities and those who have children with disabilities, lose access to Medicaid due to the de-linking of Medicaid and TANF. These reasons include: inappropriate TANF agency procedures, lack of information or misinformation held by TANF staff or recipients, computer system errors that automatically kick families off the Medicaid roles at the same time they leave the TANF roles, and/or lack of follow-through or referral on the part of the TANF staff.

- States are expressing concerns that the 20 percent TANF exemption might not be realistic. There is a relatively high percentage of recipients who cannot support

themselves and/or their families with low-wage employment because of their own disability or the care needed for a dependent who has a disability, and/or inadequate and/or unavailable child care.

- There are a number of reasons that persons with disabilities are not finding jobs and losing their TANF and possibly their Medicaid benefits. Many persons with disabilities, especially those with cognitive impairments or mental illness, do not understand the process (e.g., may not return to welfare office) or are unsuccessful finding or retaining a job. A significant segment of eligible persons, including those with disabilities, have never been counted as "denied benefits" because they have not been allowed to apply or have been discouraged from applying.

- State sanctions are often designed and implemented without consideration for the needs of persons with disabilities, and accommodations are not adequately provided. For example, if the recipient fails to attend a "mandatory meeting," he or she may be removed from the rolls without a telephone call to find out why the meeting was missed. Meetings may be scheduled early in the morning, a difficult time for some people with mental illness because of medication side effects. Perhaps the client has a cognitive disability and does not understand that attendance is required.

CONCLUDING REMARKS

As stated in the introductory section of this document, the purposes of this document are to provide an overview of the key provisions of federal welfare legislation (i.e., the PRWORA and the Balanced Budget Act of 1997), a description of selected state implementation strategies, an overview of several impact studies, and a discussion of selected welfare reform implementation strategies.

As state welfare caseloads are decreasing and welfare recipients are finding jobs, states are expanding their efforts for the hard-to-place populations, including those with disabilities or caregivers of persons with disabilities. Many states have increased participation in work and self-sufficiency activities for persons with disabilities. Identification and assessment procedures for learning disabilities are being developed or improved, and a number of other training accommodations and supports are being provided for persons with disabilities (e.g., literacy training and re-configuring job requirements).

In a number of states, coordinated service systems (e.g., seamless systems of care) are taking shape despite the challenges of integrating and aligning various agency programs and services. Other interagency efforts are improving education, child care, family support, and job training. Adult education, vocational education, and vocational rehabilitation are being utilized to help recipients acquire needed job skills. A number of states are implementing initiatives to improve access to quality child care. Innovative approaches are being implemented within the states involving the CHIP program.

Although significant numbers of welfare recipients have disabilities, have a person with a disability in their families, or care for a person with a disability, specific studies examining the impacts of federal and state welfare reform upon these populations are limited and/or only in the planning or early implementation stages. Preliminary impact studies indicate that transportation is a barrier to returning to work. Those who find work continue to struggle with low paying jobs and the affordability of health insurance.

Several other concerns about welfare reform were identified including numbers of children who do not have safe, quality, and affordable child care. In addition, there is a need to update the listing of SSI eligible impairments, integrate a functional component into the overall SSI assessment process, and train personnel to adequately identify and evaluate disabilities. Although managed care has a number of advantages, services for children with disabilities may be limited (e.g., specialized services). This is an area of concern because of the increasing number of Medicaid recipients who are being required to enroll in managed care plans that provide limited services.

Many young children below age six with special needs are Medicaid eligible and require services supported by Medicaid. A number of such issues are being addressed by the states including the need to better train private providers within managed care networks regarding the medical, therapeutic, and other supports required by these young children. In addition, managed care capitation rates should be reviewed and adjusted to meet the differential service needs of children with and without special needs and their families.

It is important that state and local special education administrators work closely with their welfare and other agency partners to find solutions to the implementation issues discussed in this document as well as other issues and concerns arising from welfare reform. Solutions will need to focus on activities such as:

- Dissemination of information to parents of children with disabilities as well as adolescents with disabilities regarding TANF and Medicaid linkages (e.g., specific criteria for Medicaid eligibility).
- Development of improved disability screening and identification procedures.
- Implementation of literacy programs and other initiatives that involve school-age welfare clients.
- Increased public awareness regarding welfare reform and available interagency supports for adult and school-age recipients.
- Implementation of training programs specifically designed toward job training, job finding, job support, and other transition supports.
- Activities that support quality child care opportunities for students with disabilities and training of child care workers about disabilities.

Even though the focus of this document was on federal welfare legislation and state implementation efforts, state and local special education administrators must also work closely with vocational education, vocational rehabilitation, and welfare in the implementation of other supporting federal legislation (e.g., the Workforce Investment Act of 1998) aimed at expanding job training, adult education and literacy, and vocational rehabilitation. Specifically, all agency partners must work together to implement welfare reform legislation and achieve integrated services in a seamless delivery system (e.g., job search, job placement, and post employment follow-up for all adults, including those with disabilities).

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